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ABSTRACT

This booklet provides an overview of autism and discusses strategies for living and working with children with autism. The first section of the guide, "Understanding the Problem," addresses the characteristics of autism, including social symptoms, language difficulties, repetitive behaviors and obsessions, sensory symptoms, and unusual abilities; how autism is diagnosed, including diagnostic procedures and diagnostic criteria; causes of autism; and disorders that commonly accompany autism, such as mental retardation, seizures, and Fragile X syndrome. Descriptions of children with autism illustrate the different profiles of autism, and charts show indicators of normal development and the differences in the behaviors of infants with and without autism in communication, social relationships, and exploration of the environment. The second part of the booklet, "Finding Help and Hope," addresses ways parents and practitioners can help children with autism. It discusses improving social skills and behavior, developmental approaches, behaviorist approaches, nontraditional approaches, types of medications that are available, educational options and planning the Individualized Education Program, adolescents with autism, adults with autism, ways families can cope, and current research efforts. Questions that parents should consider when exploring treatment options are provided. The guide concludes with a list of resource books on autism and relevant organizations. (CR)

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Decade of the Brain

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MESSAGE FROM THE DIRECTOR OF THE
NATIONAL INSTITUTE OF MENTAL HEALTH

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Autism

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Autism

Isolated in worlds of their own, people with autism appear indifferent and remote and are unable to form emotional bonds with others. Although people with this baffling brain disorder can display a wide range of symptoms and disability, many are incapable of understanding other people's thoughts, feelings, and needs. Often, language and intelligence fail to develop fully, making communication and social relationships difficult. Many people with autism engage in repetitive activities, like rocking or banging their heads, or rigidly following familiar patterns in their everyday routines. Some are painfully sensitive to sound, touch, sight, or smell.

Children with autism do not follow the typical patterns of child development. In some children, hints of future problems may be apparent from birth. In most cases, the problems become more noticeable as the child slips farther behind other children the same age. Other children start off well enough. But between 18 and 36 months old, they suddenly reject people, act strangely, and lose language and social skills they had already acquired.

As a parent, teacher, or caregiver you may know the frustration of trying to communicate and connect with children or adults who have autism. You may feel ignored as they engage in endlessly repetitive behaviors. You may despair at the bizarre ways they express their inner needs. And you may feel sorrow that your hopes and dreams for them may never materialize.

But there is help—and hope. Gone are the days when people with autism were isolated, typically sent away to institutions. Today, many youngsters can be helped to attend school with other children. Methods are available to help improve their social, language, and academic skills. Even though more than 60 percent of adults with autism continue to need care throughout their lives, some programs are beginning to demonstrate that with appropriate support, many people with autism can be trained to do meaningful work and participate in the life of the community.

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Autism is found in every country and region of the world, and in families of all racial, ethnic, religious, and economic backgrounds. Emerging in childhood, it affects about 1 or 2 people in every thousand and is three to four times more common in boys than girls. Girls with the disorder, however, tend to have more severe symptoms and lower intelligence. In addition to loss of personal potential, the cost of health and educational services to those affected exceeds $3 billion each year. So, at some level, autism affects us all.

This booklet is provided by the National Institute of Mental Health (NIMH), the Federal agency that conducts and supports research on mental and brain disorders, including autism. NIMH is part of the National Institutes of Health (NIH), which is the Federal Government's primary agency for biomedical and behavioral research. Research on autism and related disorders is also sponsored by the National Institute of Child Health and Human Development (NICHD), National Institute on Deafness and Other Communication Disorders (NIDCD), and National Institute of Neurological Disorders and Stroke (NINDS).

NIMH scientists are dedicated to understanding the workings and interrelationships of the various regions of the brain, and to developing preventive measures and new treatments for disorders like autism that handicap people in school, work, and social relationships.

Up-to-date information on autism and the role of NIMH in identifying underlying causes and effective treatments are included in this pamphlet. Also described are symptoms and diagnostic procedures, treatment options, strategies for coping, and sources of information and support.

The individuals referred to in this brochure are not real, but their stories are based on interviews with parents who have children with autism.

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Understanding the Problem

Paul

Paul has always been obsessed with order. As a child, he lined up blocks, straightened chairs, kept his toothbrush in the exact same spot on the sink, and threw a tantrum when anything was moved. Paul could also become aggressive. Sometimes, when upset or anxious, he would suddenly explode, throwing a nearby object or smashing a window. When overwhelmed by noise and confusion, he bit himself or picked at his nails until they bled. At school, where his schedule and environment could be carefully structured, his behavior was more normal. But at home, amid the unpredictable, noisy hubbub of a large family, he was often out of control. His behavior made it harder and harder for his parents to care for him at home and also meet their other children's needs. At that time—more than 10 years ago—much less was known about the disorder and few therapeutic options were available. So, at age 9, his parents placed him in a residential program where he could receive 24-hour supervision and care.

Alan

As an infant, Alan was playful and affectionate. At 6 months old, he could sit up and crawl. He began to walk and say words at 10 months and could count by 13 months. One day, in his 18th month, his mother found him sitting alone in the kitchen, repeatedly spinning the wheels of her vacuum cleaner with such persistence and concentration, he didn't respond when she called. From that day on, she recalls, "It was as if someone had pulled a shade over him." He stopped talking and relating to others. He often tore around the house like a demon. He became fixated on electric lights, running around the house turning them on and off. When made to stop, he threw a tantrum, kicking and biting anyone within reach.

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Janie

From the day she was born, Janie seemed different from other infants. At an age when most infants enjoy interacting with people and exploring their environment, Janie sat motionless in her crib and didn't respond to rattles or other toys. She didn't seem to develop in the normal sequence, either. She stood up before she crawled, and when she began to walk, it was on her toes. By 30 months old, she still wasn't talking. Instead, she grabbed things or screamed to get what she wanted. She also seemed to have immense powers of concentration, sitting for hours looking at a toy in her hand. When Janie was brought to a special clinic for evaluation, she spent an entire testing session pulling tufts of wool from the psychologist's sweater.

What is Autism?

Autism is a brain disorder that typically affects a person's ability to communicate, form relationships with others, and respond appropriately to the environment. Some people with autism are relatively high-functioning, with speech and intelligence intact. Others are mentally retarded, mute, or have serious language delays. For some, autism makes them seem closed off and shut down; others seem locked into repetitive behaviors and rigid patterns of thinking.

Although people with autism do not have exactly the same symptoms and deficits, they tend to share certain social, communication, motor, and sensory problems that affect their behavior in predictable ways.

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Differences in the Behaviors of Infants With and Without Autism

Infants with Autism	Normal Infants
Communication	
• Avoid eye contact	• Study mother's face
• Seem deaf	• Easily stimulated by sounds
• Start developing language, then abruptly stop talking altogether	• Keep adding to vocabulary and expanding grammatical usage
Social relationships	
• Act as if unaware of the coming and going of others	• Cry when mother leaves the room and are anxious with strangers
• Physically attack and injure others without provocation	• Get upset when hungry or frustrated
• Inaccessible, as if in a shell	• Recognize familiar faces and smile
Exploration of environment	
• Remain fixated on a single item or activity	• Move from one engrossing object or activity to another
• Practice strange actions like rocking or hand-flapping	• Use body purposefully to reach or acquire objects
• Sniff or lick toys	• Explore and play with toys
• Show no sensitivity to burns or bruises, and engage in self-mutilation, such as eye gouging	• Seek pleasure and avoid pain

NOTE: This list is not intended to be used to assess whether a particular child has autism. Diagnosis should only be done by a specialist using highly detailed background information and behavioral observations.

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Social symptoms

From the start, most infants are social beings. Early in life, they gaze at people, turn toward voices, endearingly grasp a finger, and even smile.

In contrast, most children with autism seem to have tremendous difficulty learning to engage in the give-and-take of everyday human interaction. Even in the first few months of life, many do not interact and they avoid eye contact. They seem to prefer being alone. They may resist attention and affection or passively accept hugs and cuddling. Later, they seldom seek comfort or respond to anger or affection. Unlike other children, they rarely become upset when the parent leaves or show pleasure when the parent returns. Parents who looked forward to the joys of cuddling, teaching, and playing with their child may feel crushed by this lack of response.

Children with autism also take longer to learn to interpret what others are thinking and feeling. Subtle social cues—whether a smile, a wink, or a grimace—may have little meaning. To a child who misses these cues, "Come here," always means the same thing, whether the speaker is smiling and extending her arms for a hug or squinting and planting her fists on her hips. Without the ability to interpret gestures and facial expressions, the social world may seem bewildering.

To compound the problem, people with autism have

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problems seeing things from another person's perspective. Most 5-year-olds understand that other people have different information, feelings, and goals than they have. A person with autism may lack such understanding. This inability leaves them unable to predict or understand other people's actions.

Some people with autism also tend to be physically aggressive at times, making social relationships still more difficult. Some lose control, particularly when they're in a strange or overwhelming environment, or when angry and frustrated. They are capable at times of breaking things, attacking others, or harming themselves. Alan, for example, may fall into a rage, biting and kicking when he is frustrated or angry. Paul, when tense or overwhelmed, may break a window or throw things. Others are self-destructive, banging their heads, pulling their hair, or biting their arms.

Language difficulties

By age 3, most children have passed several predictable milestones on the path to learning language. One of the earliest is babbling. By the first birthday, a typical toddler says words, turns when he hears his name, points when he wants a toy, and when offered something distasteful, makes it very clear that his answer is no. By age 2, most children begin to put together sentences like "See doggie," or "More cookie," and can follow simple directions.

Research shows that about half of the children diagnosed with autism remain mute throughout their lives. Some infants who later show signs of autism do coo and babble during the first 6 months of life. But they soon stop. Although they may learn to communicate using sign language or special electronic equipment, they may never speak. Others may be delayed, developing language as late as age 5 to 8.

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Those who do speak often use language in unusual ways. Some seem unable to combine words into meaningful sentences. Some speak only single words. Others repeat the same phrase no matter what the situation.

Some children with autism are only able to parrot what they hear, a condition called *echolalia*. Without persistent training, echoing other people's phrases may be the only language that people with autism ever acquire. What they repeat might be a question they were just asked, or an advertisement on television. Or out of the blue, a child may shout, "Stay on your own side of the road!"—something he heard his father say weeks before. Although children without autism go through a stage where they repeat what they hear, it normally passes by the time they are 3.

People with autism also tend to confuse pronouns. They fail to grasp that words like "my," "I," and "you," change

When Alan's teacher asks, "What is my name?" he answers, "My name is Alan."

meaning depending on who is speaking. When Alan's teacher asks, "What is my name?" he answers, "My name is Alan."

Some children say the same phrase in a variety of different situations. One child, for example, says "Get in the car," at random times throughout the day. While on the surface, her statement seems bizarre, there may be a meaningful pattern in what the child says. The child may be saying,

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"Get in the car," whenever she wants to go outdoors. In her own mind, she's associated "Get in the car," with leaving the house. Another child, who says "Milk and cookies" whenever he is pleased, may be associating his good feelings around this treat with other things that give him pleasure.

It can be equally difficult to understand the body language of a person with autism. Most of us smile when we talk about things we enjoy, or shrug when we can't answer a question. But for children with autism, facial expressions, movements, and gestures rarely match what they are saying. Their tone of voice also fails to reflect their feelings. A high-pitched, sing-song, or flat, robot-like voice is common.

Without meaningful gestures or the language to ask for things, people with autism are at a loss to let others know what they need. As a result, children with autism may simply scream or grab what they want. Temple Grandin, an exceptional woman with autism who has written two books about her disorder, admits, "Not being able to speak was utter frustration. Screaming was the only way I could communicate." Often she would logically think to herself, "I am going to scream now because I want to tell somebody I don't want to do something." Until they are taught better means of expressing their needs, people with autism do whatever they can to get through to others.

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The Story of Temple Grandin

Temple Grandin, despite a lifelong struggle with autism, earned a doctoral degree in animal science. Today, she invents equipment for managing livestock and teaches at a major university. A woman of extraordinary accomplishments, she has also written several books on animal science, autism, and her own life.

Yet at 6 months old, Temple had many of the full-blown signs of autism. When held, she would stiffen and struggle to be put down. By age 2, it was clear that she was hypersensitive to taste, sound, smell, and touch. Sounds were excruciating. Wearing clothes was torture: the feel of certain fabrics was like sandpaper grating her skin. Constantly buffeted by overpowering sensations, she screamed, raged, and threw things. At other times, she found that by focusing intently and exclusively on one item—her own hand, an apple, a spinning coin, or sand

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sifting through her fingers—she could withdraw into a temporary haven of order and predictability.

As was customary at the time, a doctor advised that Temple be institutionalized. Her mother refused and placed her in a therapeutic program for children who were speech impaired. The classes were small and highly structured. Even though the program was not designed to treat autism, the methods worked for Temple. By age 4, she began to speak and by age 5 she was able to attend kindergarten in a regular school. Temple attributes her success to several key people in her life: her mother, who persisted in finding help; her therapist, who kept her from withdrawing into an inner world; and a high school teacher who helped transform her interest in animals into a career in animal science.

Temple's insights into the needs of animals, a strongly developed ability to think visually "in pictures," and an awareness of her own special needs led her to invent equipment that has helped both livestock and, remarkably, herself. After seeing a device used to calm cattle, she created a "squeeze machine." The machine provides self-controlled pressure that helps her relax. She finds that after using the squeeze machine, she feels less aggressive and less hypersensitive. With her love of animals and her personal sensitivity as a guide, Temple has also designed humane equipment and facilities for managing cattle that are used all over the world. Her unusually strong visual sense allows her to plan and design these complex projects in her head. She can precisely envision new, complex facilities and how various pieces of equipment fit together before she draws a blueprint.

Temple Grandin's story is a powerful affirmation that autism need not keep people from realizing their potential.

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Repetitive behaviors and obsessions

Although children with autism usually appear physically normal and have good muscle control, odd repetitive motions may set them off from other children. A child might spend hours repeatedly flicking or flapping her fingers or rocking back and forth. Many flail their arms or walk on their toes. Some suddenly freeze in position. Experts call such behaviors *stereotypies* or *self-stimulation*.

Some people with autism also tend to repeat certain actions over and over. A child might spend hours lining up pretzel sticks. Or, like Alan, run from room to room turning lights on and off.

Some children with autism develop troublesome fixations with specific objects, which can lead to unhealthy or dangerous behaviors. For example, one child insists on carrying feces from the bathroom into her classroom. Other behaviors are simply startling, humorous, or embarrassing to those around them. One girl, obsessed with digital watches, grabs the arms of strangers to look at their wrists.

For unexplained reasons, people with autism demand consistency in their environment. Many insist on eating the same foods, at the same time, sitting at precisely the same place at the table every day. They may get furious if a picture is tilted on the wall, or wildly upset if their toothbrush has been moved even slightly. A minor change in their routine, like taking a different route to school, may be tremendously upsetting.

Scientists are exploring several possible explanations for such repetitive, obsessive behavior. Perhaps the order and sameness lends some stability in a world of sensory

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confusion. Perhaps focused behaviors help them to block out painful stimuli. Yet another theory is that these behaviors are linked to the senses that work well or poorly. A child who sniffs everything in sight may be using a stable sense of smell to explore his environment. Or perhaps the reverse is true: he may be trying to stimulate a sense that is dim.

Imaginative play, too, is limited by these repetitive behaviors and obsessions. Most children, as early as age 2, use their imagination to pretend. They create new uses for an object, perhaps using a bowl for a hat. Or they pretend to be someone else, like a mother cooking dinner for her "family" of dolls. In contrast, children with autism rarely pretend. Rather than rocking a doll or rolling a toy car, they may simply hold it, smell it, or spin it for hours on end.

Sensory symptoms

When children's perceptions are accurate, they can learn from what they see, feel, or hear. On the other hand, if sensory information is faulty or if the input from the various senses fails to merge into a coherent picture, the child's experiences of the world can be confusing. People with autism seem to have one or both of these problems. There may be problems in the sensory signals that reach the brain or in the integration of the sensory signals—and quite possibly, both.

Apparently, as a result of a brain malfunction, many children with autism are highly attuned or even painfully sensitive to certain sounds, textures, tastes, and smells. Some children find the feel of clothes touching their skin so disturbing that they can't focus on anything else. For others, a gentle hug may be overwhelming. Some children cover their ears and scream at the sound of a vacuum cleaner, a distant airplane, a telephone ring, or even the wind. Temple Grandin says, "It was like having a hearing aid that picks up everything, with the volume control stuck on

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super loud." Because any noise was so painful, she often chose to withdraw and tuned out sounds to the point of seeming deaf.

In autism, the brain also seems unable to balance the senses appropriately. Some children with autism seem oblivious to extreme cold or pain, but react hysterically to things that wouldn't bother other children. A child with autism may break her arm in a fall and never cry. Another child might bash his head on the wall without a wince. On the other hand, a light touch may make the child scream with alarm.

In some people, the senses are even scrambled. One child gags when she feels a certain texture. A man with autism hears a sound when someone touches a point on his chin. Another experiences certain sounds as colors.

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Unusual abilities

Some people with autism display remarkable abilities. A few demonstrate skills far out of the ordinary. At a young age, when other children are drawing straight lines and scribbling, some children with autism are able to draw detailed, realistic pictures in three-dimensional perspective. Some toddlers who are autistic are so visually skilled that they can put complex jigsaw puzzles together. Many begin to read exceptionally early—sometimes even before they begin to speak. Some who have a keenly developed sense of hearing can play musical instruments they have never been taught, play a song accurately after hearing it once, or name any note they hear. Like the person played by Dustin Hoffman in the movie *Rain Man*, some people with autism can memorize entire television shows, pages of the phone book, or the scores of every major league baseball game for the past 20 years. However, such skills, known as *islets of intelligence* or *savant skills* are rare.

How is Autism Diagnosed?

Parents are usually the first to notice unusual behaviors in their child. In many cases, their baby seemed "different" from birth—being unresponsive to people and toys, or focusing intently on one item for long periods of time. The first signs of autism may also appear in children who had been developing normally. When an affectionate, babbling toddler suddenly becomes silent, withdrawn, violent, or self-abusive, something is wrong.

Even so, years may go by before the family seeks a diagnosis. Well-meaning friends and relatives sometimes help parents ignore the problems with reassurances that "Every child is different," or "Jamie can talk—she just doesn't *want* to!" Unfortunately, this only delays getting appropriate assessment and treatment for the child.

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Indicators of Normal Development

Age	Skills or Abilities Awareness and Thinking	Communication
birth- 3 months	Responds to new sounds Follows movement of hands with eyes Looks at objects and people	Coos and makes sounds Smiles at mother's voice
3-6 months	Recognizes mother Reaches for things	Turns head to sounds and voices Begins babbling Imitates sounds Varies cry
6-9 months	Imitates simple gestures Responds to name	Makes nonsense syllables like gaga Uses voice to get attention
9-12 months	Plays simple games Moves to reach desired objects Looks at pictures in books	Waves bye-bye Stops when told "no" Imitates new words
12-18 months	Imitates unfamiliar sounds and gestures Points to a desired object	Shakes head to mean "no" Begins using words Follows simple commands
18-24 months	Identifies parts of own body Attends to nursery rhymes Points to pictures in books	Uses two words to describe actions Refers to self by name
24-36 months	Matches shapes and objects Enjoys picture books Recognizes self in mirror Counts to ten	Joins in songs and rhythm Uses three-word phrases Uses simple pronouns Follows two instructions at a time

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Adapted from Growth and Developmental Milestones. Maryland Infants and Toddlers Program. Baltimore, MD. 1993

Movement	Social	Self-help
Waves hands and feet Grasps objects Watches movement of own hands	Enjoys being tickled and held Makes brief eye contact during feeding	Opens mouth to bottle or breast and sucks
Lifts head and chest Bangs objects in play	Notices strangers and new places Expresses pleasure or displeasure Likes physical play	Eats baby food from spoon Reaches for and holds bottle
Crawls Stands by holding on to things Claps hands Moves objects from one hand to the other	Plays peek-a-boo Enjoys other children Understands social signals like smiles or harsh tones	Chews Drinks from a cup with help
Walks holding on to furniture Deliberately lets go of an object Makes marks with a pencil or crayon	Laughs aloud during play Shows preference for one toy over another Responds to adult's change in mood	Feeds self with fingers Drinks from cup
Creeps upstairs and downstairs Walks alone Stacks blocks	Repeats a performance laughed at Shows emotions like fear or anger Returns a kiss or hug	Moves to help in dressing Indicates wet diaper
Jumps in place Pushes and pulls objects Turns pages of book one by one Uses fingers and thumb	Cries a bit when parents leave Becomes easily frustrated Pays attention to other children	Zips Removes clothes without help Unwraps things
Kicks and throws ball Runs and jumps Draws straight lines Strings beads	Pretends and plays make believe Avoids dangerous situations Initiates play Attempts to take turns	Feeds self with spoon Uses toilet with some help

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Diagnostic procedures

To date, there are no medical tests like x-rays or blood tests that detect autism. And no two children with the disorder behave the same way. In addition, several conditions can cause symptoms that resemble those of autism. So parents and the child's pediatrician need to rule out other disorders, including hearing loss, speech problems, mental retardation, and neurological problems. But once these possibilities have been eliminated, a visit to a professional who specializes in autism is necessary. Such specialists include people with the professional titles of child psychiatrist, child psychologist, developmental pediatrician, or pediatric neurologist.

Autism specialists use a variety of methods to identify the disorder. Using a standardized rating scale, the specialist closely observes and evaluates the child's language and social behavior. A structured interview is also used to elicit information from parents about the child's behavior and early development. Reviewing family videotapes, photos, and baby albums may help parents recall when each behavior first occurred and when the child reached certain developmental milestones. The specialists may also test for certain genetic and neurological problems.

Specialists may also consider other conditions that produce many of the same behaviors and symptoms as autism, such as Rett's Disorder or Asperger's Disorder. Rett's Disorder is a progressive brain disease that only affects girls but, like autism, produces repetitive hand movements and leads to loss of language and social skills. Children with Asperger's Disorder are very like high-functioning children with autism. Although they have repetitive behaviors, severe social problems, and clumsy movements, their language and intelligence are usually intact. Unlike autism, the symptoms of Asperger's Disorder typically appear later in childhood.

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Diagnostic criteria

After assessing observations and test results, the specialist makes a diagnosis of autism only if there is clear evidence of:

- poor or limited social relationships
- underdeveloped communication skills
- repetitive behaviors, interests, and activities.

People with autism generally have some impairment within each category, although the severity of each symptom may vary. The diagnostic criteria also require that these symptoms appear by age 3.

However, some specialists are reluctant to give a diagnosis of autism. They fear that it will cause parents to lose hope. As a result, they may apply a more general term that simply describes the child's behaviors or sensory deficits. "Severe communication disorder with autism-like behaviors," "multi-sensory system disorder," and "sensory integration dysfunction" are some of the terms that are used. Children with milder or fewer symptoms are often diagnosed as having Pervasive Developmental Disorder (PDD).

Although terms like Asperger's Disorder and PDD do not significantly change treatment options, they may keep the child from receiving the full range of specialized educational services available to children diagnosed with autism. They may also give parents false hope that their child's problems are only temporary.

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What Causes Autism?

It is generally accepted that autism is caused by abnormalities in brain structures or functions. Using a variety of new research tools to study human and animal brain growth, scientists are discovering more about normal development and how abnormalities occur.

The brain of a fetus develops throughout pregnancy. Starting out with a few cells, the cells grow and divide until the brain contains billions of specialized cells, called neurons. Research sponsored by NIMH and other components at the National Institutes of Health is playing a key role in showing how cells find their way to a specific area of the brain and take on special functions. Once in place, each neuron sends out long fibers that connect with other neurons. In this way, lines of communication are established between various areas of the brain and between the brain and the rest of the body. As each neuron receives a signal it releases chemicals called neurotransmitters, which pass the signal to the next neuron. By birth, the brain has evolved into a complex organ with several distinct regions and subregions, each with a precise set of functions and responsibilities.

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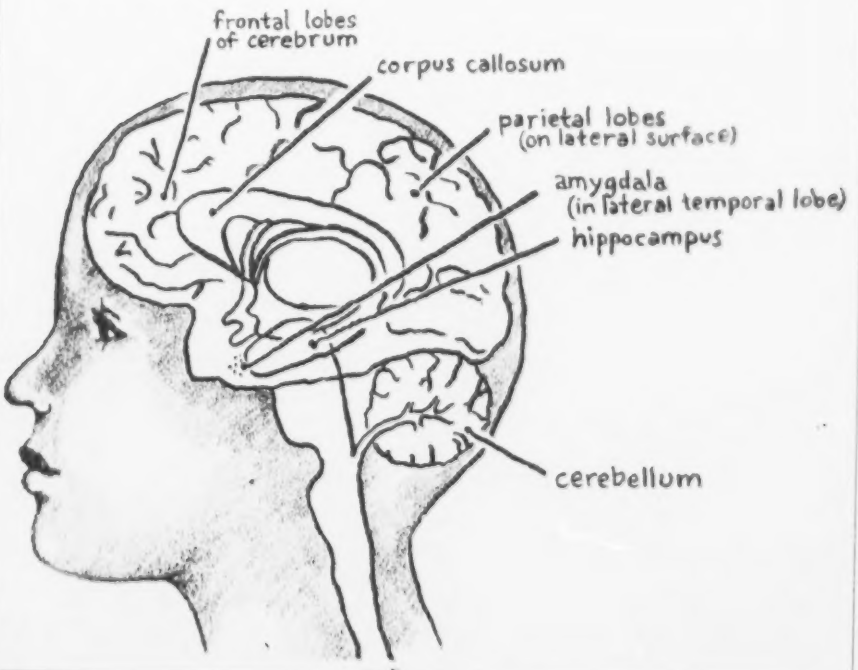
Different parts of the brain have different functions

- The hippocampus makes it possible to recall recent experience and new information
- The amygdala directs our emotional responses
- The frontal lobes of the cerebrum allow us to solve problems, plan ahead, understand the behavior of others, and restrain our impulses
- The parietal areas control hearing, speech, and language
- The cerebellum regulates balance, body movements, coordination, and the muscles used in speaking
- The corpus callosum passes information from one side of the brain to the other



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But brain development does not stop at birth. The brain continues to change during the first few years of life, as new neurotransmitters become activated and additional lines of communication are established. Neural networks are forming and creating a foundation for processing language, emotions, and thought.

However, scientists now know that a number of problems may interfere with normal brain development. Cells may migrate to the wrong place in the brain. Or, due to problems with the neural pathways or the neurotransmitters, some parts of the communication network may fail to perform. A problem with the communication network may interfere with the overall task of coordinating sensory information, thoughts, feelings, and actions.

Researchers supported by NIMH and other NIH Institutes are scrutinizing the structures and functions of the brain for clues as to how a brain with autism differs from the normal brain. In one line of study, researchers are investigating potential defects that occur during initial brain development. Other researchers are looking for defects in the brains of people already known to have autism.

Scientists are also looking for abnormalities in the brain structures that make up the limbic system. Inside the limbic system, an area called the amygdala is known to help regulate aspects of social and emotional behavior. One study of high-functioning children with autism found that the amygdala was indeed impaired but that another area of the brain, the hippocampus, was not. In another study, scientists followed the development of monkeys whose amygdala was disrupted at birth. Like children with autism, as the monkeys grew, they became increasingly withdrawn and avoided social contact.

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Differences in neurotransmitters, the chemical messengers of the nervous system, are also being explored. For example, high levels of the neurotransmitter serotonin have been found in a number of people with autism. Since neurotransmitters are responsible for passing nerve impulses in the brain and nervous system, it is possible that they are involved in the distortion of sensations that accompanies autism.

NIMH grantees are also exploring differences in overall brain function, using a technology called magnetic resonance imaging (MRI) to identify which parts of the brain are energized during specific mental tasks. In a study of adolescent boys, NIMH researchers observed that during problem-solving and language tasks, teenagers with autism were not only less successful than peers without autism, but the MRI images of their brains showed less activity. In a study of younger children, researchers observed low levels of activity in the parietal areas and the corpus callosum. Such research may help scientists determine whether autism reflects a problem with specific areas of the brain or with the transmission of signals from one part of the brain to another.

Each of these differences has been seen in some but not all the people with autism who were tested. What could this mean? Perhaps the term autism actually covers several different disorders, each caused by a different problem in the brain. Or perhaps the various brain differences are themselves caused by a single underlying disorder that scientists have not yet identified. Discovering the physical basis of autism should someday allow us to better identify, treat, and possibly prevent it.

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Factors affecting brain development

But what causes normal brain development to go awry? Some NIMH researchers are investigating genetic causes—the role that heredity and genes play in passing the disorder from one generation to the next. Others are looking at medical problems related to pregnancy and other factors.

Heredity. Several studies of twins suggest that autism—or at least a higher likelihood of some brain dysfunction—can be inherited. For example, identical twins are far more likely than fraternal twins to both have autism. Unlike fraternal twins, which develop from two separate eggs, identical twins develop from a single egg and have the same genetic makeup.

It appears that parents who have one child with autism are at slightly increased risk for having more than one child with autism. This also suggests a genetic link. However, autism does not appear to be due to one particular gene. If autism, like eye color, were passed along by a single gene, more family members would inherit the disorder. NIMH grantees, using state-of-the-art gene splicing techniques, are searching for irregular segments of genetic code that the autistic members of a family may have inherited.

Some scientists believe that what is inherited is an irregular segment of genetic code or a small cluster of three to six unstable genes. In most people, the faulty code may cause only minor problems. But under certain conditions, the unstable genes may interact and seriously interfere with the brain development of the unborn child.

A body of NIMH-sponsored research is testing this theory. One study is exploring whether parents and siblings who do not have autism show minor symptoms, such as mild social, language, or reading problems. If so, such findings would suggest that several members of a family can inherit the irregular or unstable genes, but that other as yet

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unidentified conditions must be present for the full-blown disorder to develop.

Pregnancy and other problems. Throughout pregnancy, the fetal brain is growing larger and more complex, as new cells, specialized regions, and communication networks form. During this time, anything that disrupts normal brain development may have lifelong effects on the child's sensory, language, social, and mental functioning.

For this reason, researchers are exploring whether certain conditions, like the mother's health during pregnancy, problems during delivery, or other environmental factors may interfere with normal brain development. Viral infections like rubella (also called German measles), particularly in the first three months of pregnancy, may lead to a variety of problems, possibly including autism and retardation. Lack of oxygen to the baby and other complications of delivery may also increase the risk of autism. However, there is no clear link. Such problems occur in the delivery of many infants who are not autistic, and most children with autism are born without such factors.

Are There Accompanying Disorders?

Several disorders commonly accompany autism. To some extent, these may be caused by a common underlying problem in brain functioning.

Mental retardation

Of the problems that can occur with autism, mental retardation is the most widespread. Seventy-five to 80 percent of people with autism are mentally retarded to some extent. Fifteen to 20 percent are considered severely retarded, with IQs below 35. (A score of 100 represents average intelligence.) But autism does not necessarily

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correspond with mental impairment. More than 10 percent of people with autism have an average or above average IQ. A few show exceptional intelligence.

Interpreting IQ scores is difficult, however, because most intelligence tests are not designed for people with autism. People with autism do not perceive or relate to their environment in typical ways. When tested, some areas of ability are normal or even above average, and some areas may be especially weak. For example, a child with autism may do extremely well on the parts of the test that measure visual skills but earn low scores on the language subtests.

Seizures

About one-third of the children with autism develop seizures, starting either in early childhood or adolescence. Researchers are trying to learn if there is any significance to the time of onset, since the seizures often first appear when certain neurotransmitters become active.

Since seizures range from brief blackouts to full-blown body convulsions, an electroencephalogram (EEG) can help confirm their presence. Fortunately, in most cases, seizures can be controlled with medication.

Fragile X

One disorder, Fragile X syndrome, has been found in about 10 percent of people with autism, mostly males. This inherited disorder is named for a defective piece of the X-chromosome that appears pinched and fragile when seen under a microscope.

People who inherit this faulty bit of genetic code are more likely to have mental retardation and many of the same symptoms as autism along with unusual physical features that are not typical of autism.

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Tuberous Sclerosis

There is also some relationship between autism and Tuberous Sclerosis, a genetic condition that causes abnormal tissue growth in the brain and problems in other organs. Although Tuberous Sclerosis is a rare disorder, occurring less than once in 10,000 births, about a fourth of those affected are also autistic.

Scientists are exploring genetic conditions such as Fragile X and Tuberous Sclerosis to see why they so often coincide with autism. Understanding exactly how these conditions disrupt normal brain development may provide insights to the biological and genetic mechanisms of autism.

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Finding Help and Hope

Paul

Adolescence was a good time for Paul. He seemed to relax and become more social. He became more affectionate. When approached, he would converse with people. For several months, drugs were used to help him control his aggression, but they were stopped because they caused unwanted side effects. Even so, he now rarely throws or breaks things.

Two years ago, Paul's parents were able to take advantage of new scientific understanding about autism, and they enrolled him in an innovative program that provides full-time support, enabling him to live and work within the community. Today, at age 20, he has a closely supervised job assembling booklets for a publishing company. He lives in an attractive apartment with another man who has autism and a residence supervisor. Paul loves picnics and outings to the library to check out books and cassettes. He also enjoys going home each week to visit his family. But he still demands familiarity and order. As soon as he arrives home, he moves every piece of furniture back to the location that is familiar to him.

Alan

The summer Alan was 6, after years with no apparent progress, his language began to flow. Although he reversed the meaning of pronouns, he began talking in sentences that other people could understand.

Now age 13, Alan has lost his constant obsession with lights, returning to it only when he feels stressed. He often burrows under a heavy pile of pillows, which seems to relax and comfort him. His fits of anger occur less often,

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but because he is bigger, he reacts with more force. Every now and then, he goes out of control, kicking, hitting, and biting. Once, at a shopping mall, he threw a tantrum so severe that his mother had to hold him down to control him.

At the same time, he has successfully made the transition to middle school and he is learning more quickly than before. He seems more aware of his surroundings and remembers people. He still doesn't play with other children, but often sits watching them from a window. It's as if he has become aware that he is different. He also seems more aware of his own emotions and at times he says quietly, "You sad."

Janie

Today, at age 4, Janie is enrolled in an intensive program in which she is trained at home by her mother and several specialists. She is beginning to show real progress. She now makes eye contact and has begun to talk. She can ask for things. As a result, she seems happier, less frustrated, and better able to form connections with others. She's also begun to show some remarkable skills. She can stack blocks and match objects far beyond her years. And her memory is amazing. Although her speech is often unclear, she can recite and act out entire television programs. Her parents' dream is that she will progress enough to enter a regular kindergarten next year.

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Is There Reason for Hope?

When parents learn that their child is autistic, most wish they could magically make the problem go away. They looked forward to having a baby and watching their child learn and grow. Instead, they must face the fact that they have a child who may not live up to their dreams and will daily challenge their patience. Some families deny the problem or fantasize about an instant cure. They may take the child from one specialist to another, hoping for a different diagnosis. It is important for the family to eventually overcome their pain and deal with the problem, while still cherishing hopes for their child's future. Most families realize that their lives can move on.

Today, more than ever before, people with autism can be helped. A combination of early intervention, special education, family support, and in some cases, medication, is helping increasing numbers of children with autism to live more normal lives. Special interventions and education programs can expand their capacity to learn, communicate, and relate to others, while reducing the severity and frequency of disruptive behaviors. Medications can be used to help alleviate certain symptoms. Older children and adults like Paul may also benefit from the treatments that are available today. So, while no cure is in sight, it is possible to greatly improve the day-to-day life of children and adults with autism.

Today, a child who receives effective therapy and education has every hope of using his or her unique capacity to learn. Even some who are seriously mentally retarded can often master many self-help skills like cooking, dressing, doing laundry, and handling money. For such children, greater independence and self-care may be the primary training goals. Other youngsters may go on to learn basic academic skills, like reading, writing, and simple math. Many complete high school. Some, like Temple Grandin, may even earn college degrees. Like anyone else, their personal interests provide strong incentives to learn.

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Clearly, an important factor in developing a child's long-term potential for independence and success is early intervention. The sooner a child begins to receive help, the more opportunity for learning. Furthermore, because a young child's brain is still forming, scientists believe that early intervention gives children the best chance of developing their full potential. Even so, no matter when the child is diagnosed, it's never too late to begin treatment.

Can Social Skills and Behavior Be Improved?

A number of treatment approaches have evolved in the decades since autism was first identified. Some therapeutic programs focus on developing skills and replacing dysfunctional behaviors with more appropriate ones. Others focus on creating a stimulating learning environment tailored to the unique needs of children with autism.

Researchers have begun to identify factors that make certain treatment programs more effective in reducing—or reversing—the limitations imposed by autism. Treatment programs that build on the child's interests, offer a predictable schedule, teach tasks as a series of simple steps, actively engage the child's attention in highly structured activities, and provide regular reinforcement of behavior, seem to produce the greatest gains.

Parent involvement has also emerged as a major factor in treatment success. Parents work with teachers and therapists to identify the behaviors to be changed and the skills to be taught. Recognizing that parents are the child's earliest teachers, more programs are beginning to train parents to continue the therapy at home. Research is beginning to suggest that mothers and fathers who are trained to work with their child can be as effective as professional teachers and therapists.

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Developmental approaches

Professionals have found that many children with autism learn best in an environment that builds on their skills and interests while accommodating their special needs. Programs employing a developmental approach provide consistency and structure along with appropriate levels of stimulation. For example, a predictable schedule of activities each day helps children with autism plan and organize their experiences. Using a certain area of the classroom for each activity helps students know what they are expected to do. For those with sensory problems, activities that sensitize or desensitize the child to certain kinds of stimulation may be especially helpful.

In one developmental preschool classroom, a typical session starts with a physical activity to help develop balance, coordination, and body awareness. Children string beads, piece puzzles together, paint and participate in other structured activities. At snack time, the teacher encourages social interaction and models how to use language to ask for more juice. Later, the teacher stimulates creative play by prompting the children to pretend being a train. As in any classroom, the children learn by doing.

Although higher-functioning children may be able to handle academic work, they too need help to organize the task and avoid distractions. A student with autism might be assigned the same addition problems as her classmates. But instead of assigning several pages in the textbook, the teacher might give her one page at a time or make a list of specific tasks to be checked off as each is done.

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Behaviorist approaches

When people are rewarded for a certain behavior, they are more likely to repeat or continue that behavior. Behaviorist training approaches are based on this principle. When children with autism are rewarded each time they attempt or perform a new skill, they are likely to perform it more often. With enough practice, they eventually acquire the skill. For example, a child who is rewarded whenever she looks at the therapist may gradually learn to make eye contact on her own.

Dr. O. Ivar Lovaas pioneered the use of behaviorist methods for children with autism more than 25 years ago. His methods involve time-intensive, highly structured, repetitive sequences in which a child is given a command and rewarded each time he responds correctly. For example, in teaching a young boy to sit still, a therapist might place him in front of chair and tell him to sit. If the child doesn't respond, the therapist nudges him into the chair. Once seated, the child is immediately rewarded in some way. A reward might be a bit of chocolate, a sip of juice, a hug, or applause—whatever the child enjoys. The process is repeated many times over a period of up to two hours. Eventually, the child begins to respond without being nudged and sits for longer periods of time. Learning to sit still and follow directions then provides a foundation for learning more complex behaviors. Using this approach for up to 40 hours a week, some children may be brought to the point of near-normal behavior. Others are much less responsive to the treatment.

However, some researchers and therapists believe that less intensive treatments, particularly those begun early in a child's life, may be more efficient and just as effective. So, over the years, researchers sponsored by NIMH and other agencies have continued to study and modify the behaviorist approach. Today, some of these behaviorist treatment programs are more individualized and built around the child's own interests and capabilities. Many programs also

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involve parents or other non-autistic children in teaching the child. Instruction is no longer limited to a controlled environment, but takes place in natural, everyday settings. Thus, a trip to the supermarket may be an opportunity to practice using words for size and shape. Although rewarding desired behavior is still a key element, the rewards are varied and appropriate to the situation. A child who makes eye contact may be rewarded with a smile, rather than candy. NIMH is funding several types of behaviorist treatment approaches to help determine the best time for treatment to start, the optimum treatment intensity and duration, and the most effective methods to reach both high- and low-functioning children.

Nonstandard approaches

In trying to do everything possible to help their children, many parents are quick to try new treatments. Some treatments are developed by reputable therapists or by parents of a child with autism, yet when tested scientifically, cannot be proven to help. Before spending time and money and possibly slowing their child's progress, the family should talk with experts and evaluate the findings of objective reviewers. Following are some of the approaches that have not been shown to be effective in treating the majority of children with autism:

- **Facilitated Communication**, which assumes that by supporting a nonverbal child's arms and fingers so that he can type on a keyboard, the child will be able to type out his inner thoughts. Several scientific studies have shown that the typed messages actually reflect the thoughts of the person providing the support.

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- **Holding Therapy**, in which the parent hugs the child for long periods of time, even if the child resists. Those who use this technique contend that it forges a bond between the parent and child. Some claim that it helps stimulate parts of the brain as the child senses the boundaries of her own body. There is no scientific evidence, however, to support these claims.

- **Auditory Integration Training**, in which the child listens to a variety of sounds with the goal of improving language comprehension. Advocates of this method suggest that it helps people with autism receive more balanced sensory input from their environment. When tested using scientific procedures, the method was shown to be no more effective than listening to music.

- **Dolman/Delcato Method**, in which people are made to crawl and move as they did at each stage of early development, in an attempt to learn missing skills. Again, no scientific studies support the effectiveness of the method.

It is critical that parents obtain reliable, objective information before enrolling their child in any treatment program. Programs that are not based on sound principles and tested through solid research can do more harm than good. They may frustrate the child and cause the family to lose money, time, and hope.

Selecting a treatment program

Parents are often disappointed to learn that there is no single best treatment for all children with autism; possibly not even for a specific child.

Even after a child has been thoroughly tested and formally diagnosed, there is no clear "right" course of action. The diagnostic team may suggest treatment methods and service providers, but ultimately it is up to the parents to

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consider their child's unique needs, research the various options, and decide.

Above all, parents should consider their own sense of what will work for their child. Keeping in mind that autism takes many forms, parents need to consider whether a specific program has helped children like their own.

At the back of this pamphlet is a list of books and associations that provide more detailed information about each form of therapy and referrals to qualified treatment providers.

Exploring Treatment Options

Parents may find these questions helpful as they consider various treatment programs:

- How successful has the program been for other children?
- How many children have gone on to placement in a regular school and how have they performed?
- Do staff members have training and experience in working with children and adolescents with autism?
- How are activities planned and organized?
- Are there predictable daily schedules and routines?
- How much individual attention will my child receive?
- How is progress measured? Will my child's behavior be closely observed and recorded?
- Will my child be given tasks and rewards that are personally motivating?
- Is the environment designed to minimize distractions?
- Will the program prepare me to continue the therapy at home?
- What is the cost, time commitment, and location of the program?

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What Medications are Available?

No medication can correct the brain structures or impaired nerve connections that seem to underlie autism. Scientists have found, however, that drugs developed to treat other disorders with similar symptoms are sometimes effective in treating the symptoms and behaviors that make it hard for people with autism to function at home, school, or work. It is important to note that none of the medications described in this section has been approved for autism by the Food and Drug Administration (FDA). The FDA is the Federal agency that authorizes the use of drugs for specific disorders.

Medications used to treat anxiety and depression are being explored as a way to relieve certain symptoms of autism. These drugs include fluoxetine (Prozac™), fluvoxamine (Luvox™), sertraline (Zoloft™), and clomipramine (Anafranil™). Some scientists believe that autism and these disorders may share a problem in the functioning of the neurotransmitter serotonin, which these medications apparently help.

One study found that about 60 percent of patients with autism who used fluoxetine became less distraught and aggressive. They became calmer and better able to handle changes in their routine or environment. However, fenfluramine, another medication that affects serotonin levels, has not proven to be helpful.

People with an anxiety disorder called obsessive-compulsive disorder (OCD), like people with autism, are plagued by repetitive actions they can't control. Based on the premise that the two disorders may be related, one NIMH research study found that clomipramine, a medication used to treat OCD, does appear to be effective in reducing obsessive, repetitive behavior in some people with autism.

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Children with autism who were given the medication also seemed less withdrawn, angry, and anxious. But more research needs to be done to see if the findings of this study can be repeated.

Some children with autism experience hyperactivity, the frenzied activity that is seen in people with attention deficit hyperactivity disorder (ADHD). Since stimulant drugs like Ritalin™ are helpful in treating many people with ADHD, doctors have tried them to reduce the hyperactivity sometimes seen in autism. The drugs seem to be most effective when given to higher-functioning children with autism who do not have seizures or other neurological problems.

Because many children with autism have sensory disturbances and often seem impervious to pain, scientists are also looking for medications that increase or decrease the transmission of physical sensations. Endorphins are natural painkillers produced by the body. But in certain people with autism, the endorphins seem to go too far in suppressing feeling. Scientists are exploring substances that block the effects of endorphins, to see if they can bring the sense of touch to a more normal range. Such drugs may be helpful to children who experience too little sensation. And once they can sense pain, such children could be less likely to bite themselves, bang their heads, or hurt themselves in other ways.

Chlorpromazine, thecridazine, and haloperidol have also been used. Although these powerful drugs are typically used to treat adults with severe psychiatric disorders, they are sometimes given to people with autism to temporarily reduce agitation, aggression, and repetitive behaviors. However, since major tranquilizers are powerful medications that can produce serious and sometimes permanent side effects, they should be prescribed and used with extreme caution.

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Vitamin B6, taken with magnesium, is also being explored as a way to stimulate brain activity. Because vitamin B6 plays an important role in creating enzymes needed by the brain, some experts predict that large doses might foster greater brain activity in people with autism. However, clinical studies of the vitamin have been inconclusive and further study is needed.

Like drugs, vitamins change the balance of chemicals in the body and may cause unwanted side effects. For this reason, large doses of vitamins should only be given under the supervision of a doctor. This is true of all vitamins and medications.

What are the Educational Options?

The Individuals with Disabilities Education Act of 1990 assures a free and appropriate public education to children with diagnosed learning deficits. The 1991 version of the law extended services to preschoolers who are developmentally delayed. As a result, public schools must provide services to handicapped children including those age 3 to 5. Because of the importance of early intervention, many states also offer special services to children from birth to age 3.

The school may also be responsible for providing whatever services are needed to enable the child to attend school and learn. Such services might include transportation, speech therapy, occupational therapy, and any special equipment. Federally funded Parent Training Information Centers and Protection and Advocacy Agencies in each state can provide information on the rights of the family and child.

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By law, public schools are also required to prepare and carry out a set of specific instructional goals for every child in a special education program. The goals are stated as specific skills that the child will be taught to perform. The list of skills make up what is known as an "IEP"—the child's Individualized Educational Program. The IEP serves as an agreement between the school and the family on the educational goals. Because parents know their child best, they play an important role in creating this plan. They work closely with the school staff to identify which skills the child needs most.

In planning the IEP, it's important to focus on what skills are critical to the child's well-being and future development. For each skill, parents and teachers should consider these questions: Is this an important life skill? What will happen if the child isn't trained to do this for herself?

Such questions free parents and teachers to consider alternatives to training. After several years of valiant effort to teach Alan to tie his shoelaces, his parents and teachers decided that Alan could simply wear sneakers with Velcro fasteners, and dropped the skill from Alan's IEP. After Alan struggled in vain to memorize the multiplication table, they decided to teach him to use a calculator.

A child's success in school should not be measured against standards like mastering algebra or completing high school. Rather, progress should be measured against his or her unique potential for self-care and self-sufficiency as an adult.

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Adolescence

For all children, adolescence is a time of stress and confusion. No less so for teenagers with autism. Like all children, they need help in dealing with their budding sexuality. While some behaviors improve in the teenage years, some get worse. Increased autistic or aggressive behavior may be one way some teens express their newfound tension and confusion.

The teenage years are also a time when children become more socially sensitive and aware. At the age that most teenagers are concerned with acne, popularity, grades, and dates, teens with autism may become painfully aware that they are different from their peers. They may notice that they lack friends. And unlike their schoolmates, they aren't dating or planning for a career. For some, the sadness that comes with such realization urges them to learn new behaviors. Sean Barron, who wrote about his autism in the book, *There's a Boy in Here*, describes how the pain of feeling different motivated him to acquire more normal social skills.

Can Autism be Outgrown?

At present, there is no cure for autism. Nor do children outgrow it. But the capacity to learn and develop new skills is within every child.

With time, children with autism mature and new strengths emerge. Many children with autism seem to go through developmental spurts between ages 5 and 13. Some spontaneously begin to talk—even if repetitively—around age 5 or later. Some, like Paul, become more sociable, or like Alan, more ready to learn. Over time, and with help, children may learn to play with toys appropriately, function socially, and tolerate mild changes in routine. Some children in treatment programs lose enough of their most disabling symptoms to function reasonably well in a regular classroom.

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Some children with autism make truly dramatic strides. Of course, those with normal or near-normal intelligence and those who develop language tend to have the best outcomes. But even children who start off poorly may make impressive progress. For example, one boy, after 9 years in a program that involved parents as co-therapists, advanced from an IQ of 70 to an IQ of 100 and began to get average grades at a regular school.

While it is natural for parents to hope that their child will "become normal," they should take pride in whatever strides their child does make. Many parents, looking back over the years, find their child has progressed far beyond their initial expectations.

Can Adults with Autism Live Independent Lives?

The majority of adults with autism need lifelong training, ongoing supervision, and reinforcement of skills. The public schools' responsibility for providing these services ends when the person is past school age. As the child becomes a young adult, the family is faced with the challenge of creating a home-based plan or selecting a program or facility that can offer such services.

In some cases, adults with autism can continue to live at home, provided someone is there to supervise at all times. A variety of residential facilities also provide round-the-clock care. Unlike many of the institutions years ago, today's facilities view residents as people with human needs, and offer opportunities for recreation and simple, but meaningful work. Still, some facilities are isolated from the community, separating people with autism from the rest of the world.

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Today, a few cities are exploring new ways to help people with autism hold meaningful jobs and live and work within the wider community. Innovative, supportive programs enable adults with autism to live and work in mainstream society, rather than in a segregated environment.

By teaching and reinforcing good work skills and positive social behaviors, such programs help people live up to their potential. Work is meaningful and based on each person's strengths and abilities. For example, people with autism with good hand-eye coordination who do complex, repetitive actions are often especially good at assembly and manufacturing tasks. A worker with a low IQ and few language skills might be trained to work in a restaurant sorting silverware and folding napkins. Adults with higher-level skills have been trained to assemble electronic equipment or do office work.

Based on their skills and interests, participants in such programs fill positions in printing, retail, clerical, manufacturing, and other companies. Once they are carefully trained in a task, they are put to work alongside the regular staff. Like other employees, they are paid for their labor, receive employee benefits, and are included in staff events like company picnics and retirement parties. Companies that hire people through such programs find that these workers make loyal, reliable employees. Employers find that the autistic behaviors, limited social skills, and even occasional tantrums or aggression, do not greatly affect the worker's ability to work efficiently or complete tasks.

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Like any other worker, program participants live in houses and apartments within the community. Under the direction of a residence coach, each resident shares as much as possible in tasks like meal-planning, shopping, cooking, and cleanup. For recreation, they go to movies, have picnics, and eat in restaurants. As they are ready, they are taught skills that make them more personally independent. Some take pride in having learned to take a bus on their own, or handling money they've earned themselves.

Job and residence coaches, who serve as a link between the program participants and the community, are the key to such programs. There may be as few as two adults with autism assigned to each coach. The job coach demonstrates the steps of a job to the worker, observes behavior, and regularly acknowledges good performance. The job coach also serves as a bridge between the workers with autism and their co-workers. For example, the coach steps in if a worker loses self-control or presents any problems on the job. The coach also provides training in specific social skills, such as waving or saying hello to fellow workers. At home, the residence coach reinforces social and self-help behaviors, and finds ways to help people manage their time and responsibilities.

At present, about a third of all people with autism can live and work in the community with some degree of independence. As scientific research points the way to more effective therapies and as communities establish programs that provide proper support, expectations are that this number will grow.

How Do Families Learn to Cope?

The task of rearing a child with autism is among the most demanding and stressful that a family faces. The child's screaming fits and tantrums can put everyone on edge. Because the child needs almost constant attention,

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brothers and sisters often feel ignored or jealous. Younger children may need to be reassured that they will not catch autism or grow to become like their sibling. Older children may be concerned about the prospect of having a child with autism themselves. The tensions can strain a marriage.

While friends and family may try to be supportive, they can't understand the difficulties in raising a child with autism. They may criticize the parents for letting their child "get away" with certain behaviors and announce how they would handle the child. Some parents of children with autism feel envious of their friends' children. This may cause them to grow distant from people who once gave them support.

Families may also be uncomfortable taking their child to public places. Children who throw tantrums, walk on their toes, flail their arms, or climb under restaurant tables to play with strangers' socks, can be very embarrassing. Jane's mother found that once she became willing to explain to strangers that her child has autism, people were more accepting. Paul's mother has learned to remind herself, "This is a *public* place. We have a right to be here."

Many parents feel deeply disappointed that their child may never engage in normal activities or attain some of life's milestones. Parents may mourn that their child may never learn to play baseball, drive, get a diploma, marry, or have children. However, most parents come to accept these feelings and focus on helping their children achieve what they can. Parents begin to find joy and pleasure in their child despite the limitations.

Support groups

Many parents find that others who face the same concerns are their strongest allies. Parents of children with autism tend to form communities of mutual caring and support.

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Parents gain not only encouragement and inspiration from other families' stories, but also practical advice, information on the latest research, and referrals to community services and qualified professionals. By talking with other people who have similar experiences, families dealing with autism learn they are not alone.

The Autism Society of America, listed at the close of this pamphlet, has spawned parent support groups in communities across the country. In such groups, parents share emotional support, affirmation, and suggestions for solving problems. Its newsletter, the Advocate, is filled with up-to-date medical and practical information.

Coping Strategies

The following suggestions are based on the experiences of families in dealing with autism, and on NIMH-sponsored studies of effective strategies for dealing with stress.

Work as a family. In times of stress, family members tend to take their frustrations out on each other when they most need mutual support. Despite the difficulties in finding child care, couples find that taking breaks without their children helps renew their bonds. The other children also need attention, and need to have a voice in expressing and solving problems.

Keep a sense of humor. Parents find that the ability to laugh and say, "You won't believe what our child has done now!" helps them maintain a healthy sense of perspective.

Notice progress. When it seems that all the help, love, and support is going nowhere, it's important to remember that over time, real progress is being made. Families are better able to maintain their hope if they celebrate the small signs of growth and change they see.

Take action. Many parents gain strength working with others on behalf of all children with autism. Working to win additional resources, community programs, or school

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services helps parents see themselves as important contributors to the well-being of others as well as their own child.

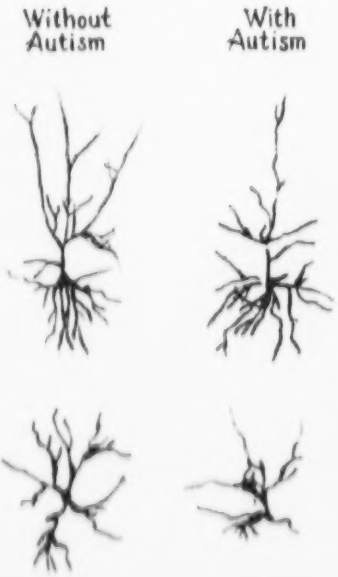
Plan ahead. Naturally, most parents want to know that when they die, their offspring will be safe and cared for. Having a plan in place helps relieve some of the worry. Some parents form a contract with a professional guardian, who agrees to look after the interests of the person with autism, such as observing birthdays and arranging for care.

What Hope Does Research Offer?

Research continues to reveal how the brain—the control center for thought, language, feelings, and behavior—carries out its functions. The National Institute of Mental Health (NIMH) funds scientists at centers across the Nation who are exploring how the brain develops, transmits its signals, integrates input from the senses, and translates all this into thoughts and behavior. In recognition of growing scientific gains in brain research, the President and Congress have officially designated the 1990s as the "Decade of the Brain."

There are new research initiatives at NIH sponsored by NIMH, NICHD, NINDS, and NIDCD. As a result, today as never before, investigators from various scientific disciplines are joining forces to unlock the mysteries of the brain. Perspective gained from research into the genetic, biochemical, physiological, and psychological aspects of autism may provide a more complete view of the disorder.

Brain Cell Defects



Research shows stunted growth—less branching—in certain nerve cells of people with autism.

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Every day, NIH-sponsored researchers are learning more about how the brain develops normally and what can go wrong in the process. Already, for example, scientists have discovered evidence suggesting that in autism, brain development slows at some point before week 30 of pregnancy.

Scientists now also have tools and techniques that allow them to examine the brain in ways that were unthought of just a few years ago. New imaging techniques that show the living brain in action permit scientists to observe with surprising clarity how the brain changes as an individual performs mental tasks, moves, or speaks. Such techniques open windows to the brain, allowing scientists to learn which brain regions are engaged in particular tasks.

In addition, recent scientific advances are permitting scientists to break new ground in researching the role of heredity in autism. Using sophisticated statistical methods along with gene splicing—a technique that enables scientists to manipulate the microscopic bits of genetic code—investigators sponsored by NIH and other institutions are searching for abnormal genes that may be involved in autism. The ability to identify irregular genes—or the factors that make a gene unstable—may lead to earlier diagnoses. Meanwhile, scientists are working to determine if there is a genetic link between autism and other brain disorders commonly associated with it, such as Tourette Disorder and Tuberous Sclerosis. New insights into the genetic transmission of these disorders, along with newly gained knowledge of normal and abnormal brain development should provide important clues to the causes of autism.

A key to developing our understanding of the human brain is research involving animals. Like humans, other primates, such as chimpanzees, apes, and monkeys, have emotions, form attachments, and develop higher-level thought processes. For this reason, studies of their brain functions and behavior shed light on human development.

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Animal studies have proven invaluable in learning how disruptions to the developing brain affect behavior, sensory perceptions, and mental development and have led to a better understanding of autism.

Ultimately, the results of NIMH's extensive research program may translate into better lives for people with autism. As we get closer to understanding the brain, we approach a day when we may be able to diagnose very young children and provide effective treatment earlier in the child's development. As data accumulate on the brain chemicals involved in autism, we get closer to developing medications that reduce or reverse imbalances.

Someday, we may even have the ability to prevent the disorder. Perhaps researchers will learn to identify children at risk for autism at birth, allowing doctors and other health care professionals to provide preventive therapy before symptoms ever develop. Or, as scientists learn more about the genetic transmission of autism, they may be able to replace any defective genes before the infant is even born.

What are Sources of Information and Support?

Parents often find that books and movies about autism that have happy endings cheer them, but raise false hopes. In such stories, a parent's novel approach suddenly works or the child simply outgrows the autistic behaviors. But there really are no cures for autism and growth takes time and patience. Parents should seek practical, realistic sources of information, particularly those based on careful research.

Similarly, certain sources of information are more reliable than others. Some popular magazines and newspapers are quick to report new "miracle cures" before they have been

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thoroughly researched. Scientific and professional materials, such as those published by the Autism Society of America and other organizations that take the time to thoroughly evaluate such claims, provide current information based on well-documented data and carefully controlled clinical research.

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Resources

The following resources provide a good starting point for gaining insight, practical information, and support. Further information on autism can be found at libraries, book stores, and local chapters of the Autism Society of America.

Books for parents

Baron-Cohen, S., and Bolton, B. *Autism: The Facts*. New York: Oxford University Press, 1993.

Harris, S., and Handelman, J. eds. *Preschool Programs for Children with Autism*. Austin, TX: PRO-ED, 1993.

Hart, C. *A Parent's Guide to Autism*. New York: Simon & Schuster, Pocket Books, 1993.

Lovaas, O. *Teaching Developmentally Disabled Children: The ME Book*. Austin, TX: PRO-ED, 1981.

May, J. *Circles of Care and Understanding: Support Groups for Fathers of Children with Special Needs*. Bethesda, MD: Association for the Care of Children's Health, 1993.

Powers, M. *Children with Autism: A Parents' Guide*. Rockville, MD: Woodbine House, 1989.

Sacks, O. *An Anthropologist on Mars*. New York: Knopf, 1995.

Advocacy Manual: A Parent's How-to Guide for Special Education Services. Pittsburgh: Learning Disabilities Association of America, 1992.

Directory for Exceptional Children: A Listing of Educational and Training Facilities. Boston: Porter Sargent Publications, 1994.

Pocket Guide to Federal Help for Individuals with Disabilities. Pueblo, CO: U.S. Government Printing Office, Consumer Information Center.

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Books for children

Amenta, C. *Russell is Extra Special.* New York: Magination Press, 1992.

Gold, P. *Please Don't Say Hello.* New York: Human Sciences Press/Plenum Publications, 1986.

Katz, L. and Ritvo, E. *Joey and Sam.* Northridge, CA: Real Life Storybooks, 1993.

Books for teachers and other interested professionals

Aarons, M., and Gittens, T. *The Handbook of Autism: A Guide for Parents and Professionals.* New York: Tavistock/Routledge, 1992.

American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders,* Fourth Edition. Washington, D.C.: American Psychiatric Association, 1994.

Groden, G., and Baron, M., eds. *Autism: Strategies for Change.* New York: Gardner Press, 1988.

Simmons, J. *The Hidden Child.* Rockville, MD: Woodbine House, 1987.

Simpson, R., and Zionts, P. *Autism: Information and Resources for Parents, Families, and Professionals.* Austin, TX: PRO-ED, 1992.

Smith, M. *Autism and Life in the Community: Successful Interventions for Behavioral Challenges.* Baltimore: Paul H. Brookes Publishing Co., 1990.

Smith, M., Belcher, R., and Juhrs, P. *A Guide to Successful Employment for Individuals with Autism.* Baltimore: Paul H. Brookes Publishing Co., 1995.

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Autobiographies of people dealing with autism

Barron, J., and Barron, S. *There's a Boy in Here*. New York: Simon and Schuster, 1992.

Grandin, T. *Thinking in Pictures and Other Reports From My Life with Autism*. New York: Doubleday, 1995.

Grandin, T. *Emergence: Labeled Autistic*. Novato, CA: Arena Press, 1986.

Hart, C. *Without Reason: A Family Copes with Two Generations of Autism*. New York: Harper & Row, 1989.

Maurice, C. *Let Me Hear Your Voice: A Family's Triumph over Autism*. New York: Knopf, 1993.

Miedzianik, D. *I Hope Some Love Will Want Me After Reading All This*. Nottingham England: Nottingham University, 1986.

Park, C. *The Siege*. New York: Harcourt, Brace, World, 1967.

Williams, D. *Somebody Somewhere*. New York: Times Books, 1994.

Agencies and associations

American Association of University Affiliated Programs for Persons with Developmental Disabilities (AAUAP)
8630 Fenton Street
Suite 410
Silver Spring, MD 20910
(301) 588-8252

Prepares professionals for careers in the field of developmental disabilities. Also provides technical assistance and training, and disseminates information to service providers to support the independence, productivity, integration, and inclusion into the community of persons with developmental disabilities and their families.

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American Speech-Language-Hearing Association
10801 Rockville Pike
Rockville, MD 20852
(800) 638-8255

Provides information on speech, language, and hearing disorders, as well as referrals to certified speech-language pathologists and audiologists.

The Association of Persons with Severe Handicaps (TASH)
29 West Susquehanna Avenue
Suite 210
Baltimore, MD 21204
(410) 828-8274

An advocacy group that works toward school and community inclusion of children and adults with disabilities. Provides information and referrals to services. Publishes a newsletter and journal.

The Autism National Committee
635 Ardmore Avenue
Ardmore, PA 19003
(610)649-9139

Publishes "The Communicator," provides referrals, and sponsors an annual conference.

Autism Research Institute
4182 Adams Ave.
San Diego, CA 92116
(619) 281-7165

Publishes the quarterly journal, *Autism Research Review International*. Provides up to date information on current research.

Autism Society of America, Inc.
7910 Woodmont Avenue
Suite 650
Bethesda, MD 20814
(301) 657-0881 or (800)-3-AUTISM

Provides a wide range of services and information to families and educators. Organizes a national conference. Publishes *The Advocate*, with articles by parents and autism experts. Local chapters make referrals to regional programs and services, and

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sponsor parent support groups. Offers information on educating children with autism, including a bibliography of instructional materials for and about children with special needs.

The Beach Center on Families and Disability
3111 Haworth Hall
University of Kansas
Lawrence, KA 66045
(913) 864-7600

Provides professional and emotional support, as well as education and training materials to families with members who have disabilities. Collaborates with professionals and policy makers to influence national policy toward people with developmental disabilities.

Council for Exceptional Children
11920 Association Drive
Reston, VA 20191-1589
(703) 620-3660 or (800) 641-7824

Provides publications for educators. Can also provide referral to ERIC Clearinghouse for Handicapped and Gifted Children.

Cure Autism Now (CAN)
5225 Wilshire Boulevard
Suite 503
Los Angeles, CA 90036
(213) 549-0500

Serves as an information exchange for families affected by autism. Founded by parents dedicated to finding effective biological treatments for autism. Sponsors talks, conferences, and research.

Department of Education
Office of Special Education Programs
330 C Street, SW
Mail Stop 2651
Washington, DC 20202
(202) 205-9058, (202) 205-8824

Federal agency providing information on educational rights under the law, as well as referrals to the Parent Training Information Center and Protection and Advocacy Agency in each state.

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Division TEACCH
Campus Box 7180
University of North Carolina
Chapel Hill, NC 27599-7180
(919) 966-2173

Publishes the *Journal of Autism and Developmental Disorders*. Also offers workshops for parents and professionals.

Federation of Families for Children's Mental Health
1021 Prince Street
Alexandria, VA 22314
(703) 684-7710

Provides information, support, and referrals through local chapters throughout the country. This national parent-run organization focuses on the needs of families of children and youth with emotional, behavioral, or mental disorders.

Indiana Resource Center on Autism
Institute for the Study of Developmental Disabilities
Indiana University
2853 East Tenth Street
Bloomington, IN 47408-2601
(812) 855-6508

Offers publications, films and videocassettes on a range of topics related to autism.

National Alliance for Autism Research
414 Wall Street, Research Park
Princeton, NJ 08540
(888)-777-NAAR; (609) 430-9160

Dedicated to advancing biomedical research into the causes, prevention, and treatment of the autism spectrum disorders. Sponsors research and conferences.

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National Information Center for Children and Youth with Disabilities (NICHCY)
P.O. Box 1492
Washington, DC 20013-1492
(800) 695-0285

Publishes information for the public and professionals in helping youth become participating members of the home and the community.

University of California at Los Angeles (UCLA)
Department of Psychology
1282-A Franz Hall
P.O. Box 951563
Los Angeles, CA 90095-1563
(310) 825-2319

Provides information on Lovaas treatment methods and behavior modification approaches.

Other National Institutes of Health agencies that sponsor research on autism and related disorders

National Institute of Child Health and Human Development
P.O. Box 29111
Washington, DC 20040
(301) 496-5133

National Institute on Deafness and Other Communication Disorders
31 Center Drive
MSC 2320, Room 3C35
Bethesda, MD 20892
(800) 241-1044, (301) 496-7243

National Institute of Neurological Disorders and Stroke
P.O. Box 5801
Bethesda, MD 20824
(800) 352-9424, (301) 496-5751

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